



The Finnish Register of Visual Impairment Annual Statistics 2020

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What is the Finnish Register of Visual Impairment?

The purpose of the Finnish Register of Visual Impairment is to study the incidence of visual impairment in Finland. The Register serves as a basis for preventive measures and treatment of visual impairment, as well as for planning of rehabilitation and other special services for persons with visual impairment. In addition, the Register provides research material on ophthalmological diseases and visual impairment. It also aims to promote and support research in the field.

The Register is maintained by the Finnish Federation of The Visually Impaired and is subject to the National Institute for Health and Welfare (THL). The National Board of Health established the Register in 1983. The operation of the Register is regulated by the Act (552/2019) on secondary use of social and health data. Health care authorities, institutions and personnel are, under the above-mentioned Act, responsible to forward to the Register such information on persons with visual impairment as is specified in the Decree.

Notification of visual impairment

Notification must be made by a specialist in ophthalmology or the ophthalmological unit of a hospital. Notification must be made if the corrected visual acuity is permanently less than 0.3 in the better eye of the patient, or if the person must for some other reason be considered comparable with a person with permanent visual impairment as described above.

Data on the Register

A notification form is used to compile personal data of persons with visual impairment and to record information on the nature (diagnoses), severity (visual acuity and visual field) and aetiology of the impairment, on multiple impairments and on the patient's visual ability in relation to reading and moving about. In connection with the updating of records, the Central Population Records provide information on the mother tongue, marital status and possible date of death of persons with visual impairment. The Central Statistical Office reports the cause of death.

Information compiled in the Finnish Register of Visual Impairment is confidential. Information concerning an individual with a visual impairment is not released to an outsider without the approval of the National Research and Development Centre for Welfare and Health.

Maintenance of the Register

A central goal of the Register is to compile as comprehensive as possible a data base on visual impairment in order to serve those interested. Special statistics are drawn up on the basis of records compiled in the Register. Central statistics illustrating the profile of visual impairment can be found in the statistical section of the annual report released by the Register.

Promotion of research on visual impairment

The Register promotes research on visual impairment by providing special statistics based on its records, and bibliographical references to researchers and students. In addition, the Register surveys study subjects related to visual impairment, maintains contacts with researchers in the field, takes part in joint research projects and international activities, and organizes research seminars.

Administration, personnel and contact addresses

The Register operates on the premises of the Finnish Federation of the Visually Impaired in Helsinki. Register staff:

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Annual Statistics 2020

The register has gathered information about the visually handicapped for 37 years (1.1.1983-). It is estimated that there are 50,000 - 60,000 visually impaired people in Finland (the population is 5,5 millions). The register contains information on 60 321 v.i. persons, of whom 17 922 were alive (31.12.2020). 1,800 - 2,000 new registrations are made annually. New entries received in the past few years have not changed the profile of visual impairment formed on the basis of the register. It can be assumed that the register contains a representative sample of those v.i's who have been using ophthalmological health care services in Finland since the year 1983.

Our register is not complete, we are on sample basis. Therefore the main distributions describing the registered persons are presented in the following tables as relative frequencies (%-distributions).

Table 1. Gender

Registered visual impairment in Finland in 2020 (total and new registerations)

| | Total % | New 2020 % |
|--------|---------|------------|
| Female | 60.0 | 64.8 |
| Male | 40.0 | 35.2 |
| Total | 100.0 | 100.0 |
| Ν | 17 922 | 1458 |

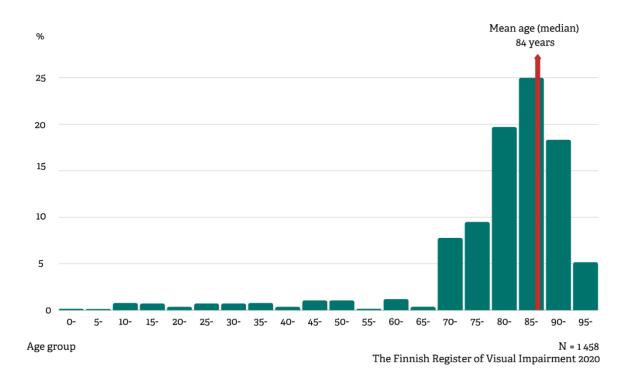
Table 2. Age groups

Registered visual impairment in Finland in 2020 (total and new registerations)

| Age | Total % | New 2020 % |
|---|--|-----------------------------------|
| 0 – 14 | 2.7 | 3.2 |
| 15 – 24 | 3.8 | 1.0 |
| 25 - 34 | 4.9 | 1.4 |
| 35 - 44 | 5.0 | 1.1 |
| 45 - 54 | 6.0 | 2.1 |
| 55 - 64 | 8.2 | 2.5 |
| 65 - 74 | 12.4 | 11.2 |
| 75 - 84 | 20.2 | 29.1 |
| 85 + | 37.0 | 48.4 |
| 0 | 87 | |
| Total | 100.0 | 100.0 |
| | | 100.0 1 458 |
| Total | 100.0 | |
| Total N | 100.0 17 922 | 1 458 |
| Total <u>N</u> 0 - 17 | 100.0 17 922 3.7 | 1 458 3.6 |
| Total N 0 - 17 18 - 39 | 100.0 17 922 3.7 10.1 | 1 458 3.6 2.7 |
| Total N 0 - 17 18 - 39 40 - 64 | 100.0 17 922 3.7 10.1 16.7 | 1 458 3.6 2.7 4.9 |

Figure 1. Age groups

New registrants in Finland in 2020 (N = 1.458)



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Figure 2. Age and gender

New registrants in Finland in 2020 (N = 1.458)



Table 3. Principal diagnoses of Visual Impairment by age groups

Registered visual impairment in Finland in 2020, total distribution and new registerations

| A. AGE GROUP 0 - 17 YEARS | Total % | New 2020 % |
|--|---|---|
| Disorders of optic nerve and visual pathways | 29.8 | 19.2 |
| - cortical blindness | 17.0 | 9.6 |
| Congenital anomalies of eye | 22.2 | 13.5 |
| Hereditary retinal dystrophies | 11.4 | 17.3 |
| Amblyopia NUD | 8.5 | 11.5 |
| Albinism | 5.5 | 1.9 |
| Nystagmus | 5.3 | 7.7 |
| ROP, retinopathy of prematurity | 3.3 | 3.8 |
| Disorders of refraction and accomodation | 3.5 | 3.8 |
| Amaurosis NUD | 2.1 | 1.9 |
| Other diagnoses | 8.4 | 19.4 |
| 0 - 17 years total (total N = 657 , new | 100.0 | 100 |
| cases $N = 52$) | | .0 |
| | | |
| B. AGE GROUP 18 - 64 YEARS | Total % | New 2020 % |
| B. AGE GROUP 18 - 64 YEARS Hereditary retinal dystrophies | Total % 20.9 | 2020 |
| _ | | 2020 % |
| – Hereditary retinal dystrophies | 20.9 | 2020 % 19.9 |
| – Hereditary retinal dystrophies Disorders of optic nerve and visual pathways | 20.9 20.4 | 2020 % 19.9 9.9 |
| | 20.9 20.4 10.7 | 2020 % 19.9 9.9 3.5 |
| – Hereditary retinal dystrophies Disorders of optic nerve and visual pathways - optic atrophy Congenital anomalies of eye | 20.9 20.4 10.7 14.4 | 2020 % 19.9 9.9 3.5 2.1 |
| – Hereditary retinal dystrophies Disorders of optic nerve and visual pathways - optic atrophy Congenital anomalies of eye Amblyopia NUD | 20.9 20.4 10.7 14.4 2.6 | 2020 % 19.9 9.9 3.5 2.1 4.3 |
| – Hereditary retinal dystrophies Disorders of optic nerve and visual pathways - optic atrophy Congenital anomalies of eye Amblyopia NUD Diabetic retinopathy | 20.9 20.4 10.7 14.4 2.6 6.3 | 2020 % 19.9 9.9 3.5 2.1 4.3 4.3 |
| Hereditary retinal dystrophies Disorders of optic nerve and visual pathways - optic atrophy Congenital anomalies of eye Amblyopia NUD Diabetic retinopathy Visual field defectes, other vis. disturbances | 20.9 20.4 10.7 14.4 2.6 6.3 | 2020 % 19.9 9.9 3.5 2.1 4.3 4.3 |
| Hereditary retinal dystrophies Disorders of optic nerve and visual pathways - optic atrophy Congenital anomalies of eye Amblyopia NUD Diabetic retinopathy Visual field defectes, other vis. disturbances (excl amblyopia) | 20.9 20.4 10.7 14.4 2.6 6.3 3.6 | 2020 % 19.9 9.9 3.5 2.1 4.3 4.3 4.3 |
| Hereditary retinal dystrophies Disorders of optic nerve and visual pathways - optic atrophy Congenital anomalies of eye Amblyopia NUD Diabetic retinopathy Visual field defectes, other vis. disturbances (excl amblyopia) ROP, retinopathy of prematurity | 20.9 20.4 10.7 14.4 2.6 6.3 3.6 3.5 | $2020 \\ \% \\ 19.9 \\ 9.9 \\ 3.5 \\ 2.1 \\ 4.3 \\ 4.3 \\ 4.3 \\ 4.3 \\ 0.0$ |
| Hereditary retinal dystrophies Disorders of optic nerve and visual pathways optic atrophy Congenital anomalies of eye Amblyopia NUD Diabetic retinopathy Visual field defectes, other vis. disturbances (excl amblyopia) ROP, retinopathy of prematurity Glaucoma | 20.9 20.4 10.7 14.4 2.6 6.3 3.6 3.5 3.1 | 2020 % 19.9 9.9 3.5 2.1 4.3 4.3 4.3 4.3 0.0 10.6 |
| Hereditary retinal dystrophies Disorders of optic nerve and visual pathways optic atrophy Congenital anomalies of eye Amblyopia NUD Diabetic retinopathy Visual field defectes, other vis. disturbances (excl amblyopia) ROP, retinopathy of prematurity Glaucoma High myopia (myopia maligna) | 20.9 20.4 10.7 14.4 2.6 6.3 3.6 3.5 3.1 7.7 | 2020 % 19.9 3.5 2.1 4.3 4.3 4.3 4.3 0.0 10.6 1.4 |

| Disorders of cornea | 1.8 | 4.3 |
|--|---------|-----------|
| Other diagnoses | 8.9 | 33.2 |
| 18 - 64 years total (total N = 4 793, new | 100.0 | 100 |
| cases $N = 141$) | | .0 |
| C. AGE GROUP 65+ YEARS | Total % | New |
| C. AGE GROUP 05+ TEARS | | 2020 % |
| – AMD, Age-related macular degeneration | 57.7 | 70.1 |
| Glaucoma | 10.9 | 14.6 |
| Hereditary retinal dystrophies | 6.1 | 0.8 |
| Disorders of optic nerve and visual pathways | 3.6 | 1.2 |
| Diabetic retinopathy | 3.0 | 1.5 |
| Amblyopia NUD | 2.7 | 0.3 |
| Disorders of cornea | 2.5 | 2.0 |
| Retinal hole | 1.7 | 0.5 |
| High myopia (myopia maligna) | 1.5 | 0.5 |
| Retinal vascular occlusion | 1.4 | 2.9 |
| Other diagnoses | 8.9 | 5.6 |
| 65+ years total (total N = 12 472, new | 100.0 | 100 |
| cases N = 1 295) | | .0 |

Coding manual for Medical Eye Services, 1980, Based on ICD-9

Figure 3 Principal Diagnoses of Visual Impairment

Registered visual impairment in Finland in 2020 (N = 17922)

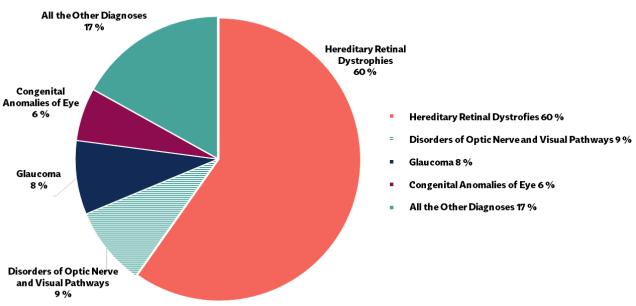


Table 4. Multiple Impairment and diabetes

Registered visual impairment in Finland in 2020 (total and new registerations)

| | Total % | New 2020 % |
|-----------------------|------------|---------------|
| Diabetes | 8.8 | 11.3 |
| Hearing | 5.6 | 6.1 |
| Learning disabilities | 4.7 | 1.2 |
| Mobility | 4.3 | 3.1 |
| CP, Cerebral Palsy | 2.3 | 0.4 |
| Ν | 17 922 | 1 458 |

Table 5. Age at onset of Visual Impairment

Registered visual impairment in Finland in 2020 (total and new registerations)

| | Total % | New 2020 |
|-------------|---------|----------|
| | | % |
| 0 | 10.0 | 1.4 |
| 1 - 17 | 5.1 | 1.6 |
| 18 – 39 | 7.0 | 1.2 |
| 40 - 64 | 9.8 | 2.6 |
| 65+ | 34.2 | 45.1 |
| Unknown/not | 33.9 | 48.1 |
| reported | | |
| Total | 100.0 | 100.0 |
| Ν | 17 922 | 1 458 |

Table 6. Categories of Visual Impairment by WHO's definition

Registered visual impairment in Finland in 2020 (N = 17922)

| | Visual acuity | Visu al field (ø) | Total % | New 2020 % |
|----------------------------|-----------------------------------|----------------------------|------------|---------------|
| 1 Moderate low | less than 0.3 $\rightarrow \geq$ | | 59.3 | 66.5 |
| vision | 0.1 | | | |
| 2 Severe low | less than 0.1 $\rightarrow \geq$ | | 11.0 | 8.1 |
| vision | 0.05 | | | |
| low vision, not specif | | | 3.1 | 0.4 |
| Low vision | less than 0.3 $\rightarrow \geq$ | | 73.5 | 75.0 |
| total | 0.05 | | | |
| 3 Profound low | less than 0.05 $\rightarrow \geq$ | less | 10.5 | 8.8 |
| vision | 0.02 | than | | |
| | | 20° | | |
| 4 Near-total | less than 0.02 \rightarrow | less | 8.8 | 5.1 |
| blindness | $1/\infty$ | than 10° | | |
| 5 Total blindness | 0 | | 2.2 | 0.1 |
| blindness not specified | | | 0.4 | 0.0 |
| Blindness total | less than 0.05 | less | 21.8 | 14.1 |
| | - | than | | - |
| | | 20° | | |
| 9 Unknown | | | 4.7 | 10.9 |
| (Other) | | | | |
| Total | | | 100. | 100.0 |
| | | | 0 | |
| Ν | | | 18 | 1 616 |
| | | | 176 | |

Figure 4 Categories of Visual Impairment by WHO's Definition with Finnish Modification

Registered visual impairment in Finland in 2020 (N = 17 922)

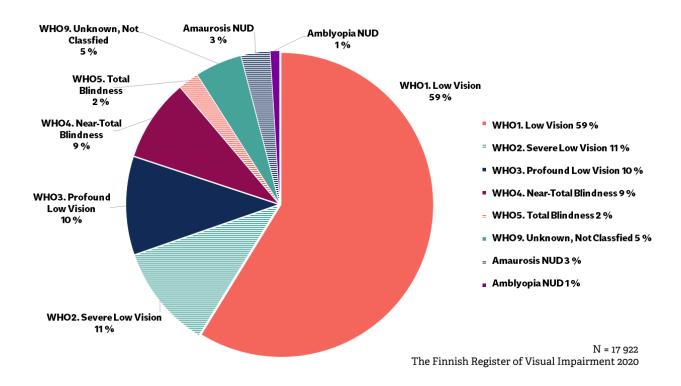


Table 7. Native Language

Registered visual impairment in Finland in 2020 (total and new registerations)

| | Total % | New 2020 % |
|---------|---------|------------|
| finnish | 90.8 | 89.3 |
| swedish | 5.8 | 7.5 |
| russian | 0.6 | 0.7 |
| sami | 0.13 | 0.0 |
| english | 0.1 | 0.1 |
| danish | 0.04 | 0.0 |

| other, unknown/not reported | 2.6 | 2.3 |
|--------------------------------|--------|-------|
| Total | 100.0 | 100.0 |
| N | 17 922 | 1 458 |

Table 8. Family Status in Age Groups

Registered visually impaired 15 – 64 years old persons % in Finland according to National Cencus in 2018%

| | Age group | | | | | |
|-------|-----------|---------|---------|------|------|-----|
| | 0 - 14 y | 15 - 24 | 25-44 y | 45- | 65 | Tot |
| | | У | | 64 y | y+ | al |
| А | 95.8 | 59.2 | 15.5 | 3.6 | 0.0 | 7.0 |
| В | - | 7.9 | 33.5 | 47.8 | 34.2 | 34. |
| | | | | | | 0 |
| С | - | 27.8 | 43.1 | 44.2 | 61.2 | 54. |
| | | | | | | 1 |
| D | 4.2 | 5.0 | 7.9 | 4.5 | 4.5 | 4.8 |
| Total | 100.0 | 100.0 | 100.0 | 100. | 100. | 10 |
| | | | | 0 | 0 | 0. |
| | | | | | | 0 |
| | | | | | | |

| А | Child in a family | |
|---|--------------------------------|--|
| В | Spouse, partner, mother/father | |

Not belonging to families Unknown, institutionalised population

Table 9. Main Type on Activity

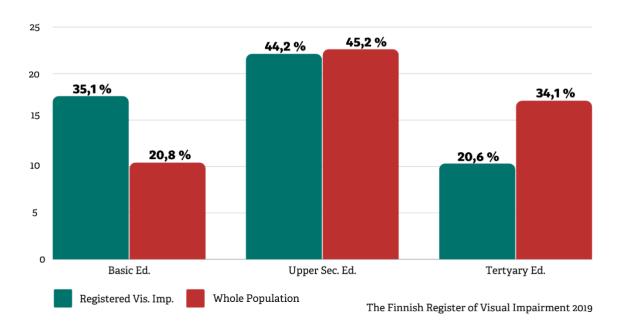
Registered visually impaired 15 - 64 year old persons in Finland according to National Cencus in 2018 compaired with the whole population

| Whole |
|----------|
| |
| popu- |
| |
| lation % |
| |
| |

| N (the registered visually impaired persons in this study) | 4 747 | |
|--|-------|-------|
| Total | 100.0 | 100.0 |
| Other or unknown | 1.9 | J 21 |
| Pensioners | 50.0 | |
| Students | 3.3 |) |
| Unemployed | 3.2 | 7 |
| Partially employed | 15.6 | J |
| Fully employed | 24.8 |) 72 |

Figure 5. Level on Education

Registered visually impaired 15 - 64 year old persons in Finland according to National Cencus in 2018 compaired with the whole population



%-distribution

Table 10. Level of Education

| | The duration | Regist.vis.imp. % | Whole population % |
|----------------------------|------------------|-------------------|-----------------------|
| | of education | 2018 | 2018 |
| | up to 9 years | 35.1 | 20.8 |
| Upper secondary : educ. | 10 - 12 years | 44.2 | 45.2 |
| Tertyary : education | 13 years + | 20.6 | 34.1 |
| Total | | 100.0 | 100. |
| N (the registered visu | ally | | 0 |
| impaired persons in t | his study) | 4 747 | |

Registered visually impaired 15 - 64 years old persons in Finland according to National Cencus in 2018 compaired with the whole population

(1) The Finnish Standard Classification of Education